

# Parent Of Ventilator-Dependent Child Welcomes Waiver

by Chuck Frame



Since we are talking about waivers, I think it might be helpful to explain what a waiver means to those of us who have been living under spend-downs for so long. It means that the additional burden of financial disaster isn't added to the already heavy load of dealing with a disabling condition. It means that the family who spends nearly all its time caring for a child at home for free doesn't have to pay additional penalties for the privilege of doing so. It means that a family of five can keep more than \$436 per month for their own expenses. It means siblings in the family can continue developing their own talents like piano lessons and college educations with less resentment toward the disabled brother or sister.

Waivers also make the statement that finally the family is recognized as part of the home care process. It doesn't change attitudes in one fell swoop, but it is one step in getting rid of the concept that when the child is in the hospital, the responsibility is all on the hospital. And if the child is ta-

ken home, the hospital relinquishes all care and the responsibility is all on the parents — an either, "We do it," or "You do it," attitude. Home care needs to be a team effort.

We have been caring for our child, Melissa, at home for three years without any help — 24 hours a day, seven days a week. The minute she entered a local hospital, we were hardly allowed to touch her, much less convince them that turning her head from one side to the other during suctioning would help the catheter go to each lung more easily. A half hour earlier we had revived her from respiratory arrest using oxygen and a rouchie bag, and suddenly we were excluded from her care. No team work.

Insurance companies foster the separation by paying for hospital care, but by being reluctant to pay for home care, no matter how healthy the patients become at home. Is this true with everyone involved? Of course not. The fact that there are families here with children at home proves that there are people from all areas involved

who've worked cooperatively to resolve these problems. Nevertheless, to have something like the waiver finally say, "We recognize your contribution and are willing to do something about it," is very significant to us.

But there is still work to be done. At present only 10 states have made applications for the model waiver available to them. That leaves a lot of families in the other states without relief. Why is there such lack of cooperation? The inconsistency from state to state is very frustrating for families who are trying to get help.

Hospitals need to develop more follow-up programs once the patient is home. Yes, there is still work to be done. But the benefits of alternative care are worth the efforts we put into overcoming these problems. The patients are healthier, costs are reduced, families have a better chance at being families and life becomes more than just existence. Melissa has been in the hospital, and Melissa has been home. And, for Melissa and her family, home is better. ●